



HCRN update



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Check out the full
Infection Protocol
articles by
following these
links!

Journal of Neurosurgery:
Pediatrics.

[A standardized protocol to
reduce cerebrospinal fluid
shunt infection: The
Hydrocephalus Clinical
Research Network Quality
Improvement Initiative.](http://thejns.org/doi/full/10.3171/2011.4.PEDS10551)

<http://thejns.org/doi/full/10.3171/2011.4.PEDS10551>

Medscape.com
[Surgical Protocol Significantly
Cuts Shunt Infection Rate.](#)

HCRN Infection Project Keeps Its Focus on Improvement

There have been big accomplishments and big changes for the longest running HCRN project over the past year, the HCRN Infection Protocol. At the time of the Network's inception the initial four HCRN centers (Primary Children's Medical Center in Salt Lake City, Children's Hospital of Alabama in Birmingham, Hospital for Sick Children in Toronto, and Texas Children's Hospital in Houston), under the direction of Dr. John Kestle, collaborated to create and subsequently implement a standardized protocol to be followed while performing shunt surgeries. The hypothesis of this quality improvement project was that reducing variation and standardizing the approach across centers would reduce the rate of infections. The Network was thrilled when the first major analysis of this multi-center data showed the protocol to be a success. Prior to the protocol's implementation, the participating centers' infection rate was, on average, 8.8%. After implementation of the protocol, however, the rate fell to a significantly lower 5.7%!

The results of Dr. Kestle's research were published in the Journal of Neurosurgery: Pediatrics. In order to help get the word of these important results out to as many people as possible, the Journal provided a link (see the box to the left) giving access to anyone interested in this project to the full article. In addition, Dr. Kestle was interviewed by Medscape.com, which also published an article about the Infection Protocol findings. Medscape.com has a much broader readership than the Journal of Neurosurgery, the primary audience of which is, appropriately, neurosurgeons. By also getting the word out through Medscape.com more people in the community are getting to know about the HCRN and the important work the network is doing.

The HCRN was excited to celebrate these collaborative accomplishments, but also believed they could do even better. As new centers joined in the HCRN's research efforts (Seattle Children's Hospital followed later by St. Louis Children's Hospital and Children's Hospital of Pittsburgh) they also adopted the HCRN Infection Protocol. In addition, over the past year, as the HCRN Investigators met in person and through regular conference calls they discussed and decided upon the changes believed would best move the Infection Protocol further toward its infection reducing goals. In January 2012 a simpler, and hopefully even more effective, Infection Protocol was put into place at all HCRN centers across the US and in Canada. The Network is excited to continue working toward its goals and looks forward to seeing future results which are hoped to reveal more of the Infection Protocol's success.



VINOH Study Up and Going

The HCRN has successfully launched a new, potentially ground-breaking study across the Network. This study, titled Ventricular Involvement in Neuropsychological Outcomes in Pediatric Hydrocephalus, or VINOH for short, is funded by a Mentored Young Investigator award from the Hydrocephalus Association received by Dr. Jay Riva-Cambrin at Primary Children's Medical Center in Salt Lake City, Utah. This study is looking into the short term implications hydrocephalus may have for school-aged patients concerning school performance, cognitive functioning, and social well-being. In addition, this study will be addressing the very important question of if and to what extent ventricle size impacts both, neuropsychological and clinical outcomes. Another exciting aspect of the VINOH study is the collaboration it has initiated across all HCRN Centers between the neurosurgical and neuropsychological staff, who are instrumental in the VINOH Study's success. It is hoped that the collaboration begun between the care providers from these two different departments may continue in the future and serve to further improve outcomes for hydrocephalus patients. Congratulations to the Primary Children's Team in getting this study going for the Network and hydrocephalus patients!



Jay Riva-Cambrin, MD and Tracy Bach, BS
Our VINOH leaders from Salt Lake City, UT

The HCRN and NIH: Getting Acquainted

HCRN investigators, representing the Network from the Children's Hospital of Alabama in Birmingham, AL, Primary Children's Medical Center and the Data Coordinating Center in Salt Lake City, UT, and St. Louis Children's Hospital in St. Louis, MO, met with the Clinical Trials group at the National Institute of Neurological Disorders and Stroke (NINDS) at the National Institute of Health (NIH) this past summer. The purpose was to help the HCRN gear up for submitting competitive applications to the NIH for future Randomized Controlled Trials planned to be developed and conducted within the Network. The HCRN had previously been awarded a 2-year Challenge Grant, given to the Network's Chair, Dr. John Kestle, which helped to provide support for the Network's infrastructure. Recently, Dr. Jay Wellons, site investigator for the Alabama Clinical Center, went through the process of applying to the NIH to fund an RCT on the management of hydrocephalus in premature infants with intraventricular hemorrhage. Meeting with the NIH staff and working together as a Network to go through the grant application process has been yet another demonstration of the HCRN's commitment and enthusiasm to get the research done that is going to make a difference in clinical care and practice. The Network as a whole has benefitted significantly from the knowledge gained in developing a relationship with staff at the NIH and learning more about how this institution functions. In addition, the NIH is also getting to know some of the members of the HCRN and learn about its goals and mission. As the research plans continue to grow and expand within the Network, we hope the relationship between the HCRN and the NIH will continue to develop as well.

HCRN Core Data Project Progress

The HCRN Core Data Project is an ongoing registry in which information about the clinical care and outcomes for patients being treated for hydrocephalus at each of the Network Clinical Centers is securely stored in one central location. The Registry is especially significant as it provides a larger number of patients for which the HCRN investigators can answer research inquiries than would be available at any one Clinical Center alone. Currently the Core Data Project has information on over 3000 medical events collected over the past four years. One of the Core Data Project's Investigators is Dr. Tamara Simon, a hospitalist with the HCRN at Seattle Children's Hospital. Dr. Simon is working specifically in the area of shunt infection and her research is funded by an NIH K-Award. Currently she is working with the Data Coordinating Center to get the data ready for analyses that will address important factors in the study of shunt infections. The Network is excited to be taking this first step in conducting analyses with data from the HCRN Core Data Project.



The HCRN Turns Five!

Dr. John Kestle wrote the following for the HCRN Blog back in September. We would like to once again share his message and celebrate this great accomplishment!

While everyone has been busy working away on HCRN studies and grant writing, HCRN's 5th birthday quietly slipped by last month. This is a significant milestone that we should all be proud of. Our first meeting in the Neurosurgical office in Salt Lake was a small group, but we had big plans. Although optimistic, I wasn't sure if we would succeed, so I am delighted that we continue to work together, grow and be productive five years down the road.

There have been many people who have worked hard to make this happen and keep it going. I would like to thank Paul Gross for his support and guidance, John Smith for his planning and writing abilities, the Executive Committee (Jim Drake, Tom Luerssen, Jerry Oakes, Jack Walker) for their counsel and guidance, and the investigators for enthusiastically supporting this endeavor and entrusting a significant portion of their academic growth to this infrastructure. Additionally of course, we wouldn't be anywhere without our outstanding team of coordinators and our expert colleagues at the Data Coordinating Center. Last but not least, thank you to our donors who have made HCRN possible.

Thank you to everyone for your cooperative approach and hard work.

Happy 5th Birthday!

HCRN and Hydrocephalus Association: A good combination for hydrocephalus patients

Co-Founder Appointed to NINDS Advisory Council

Paul Gross, Chairman of Hydrocephalus Association's (HA) Board of Directors, and, as you all know, a founding partner of the Hydrocephalus Clinical Research Network (HCRN), has been selected to join the National Advisory Neurological Disorders and Stroke Council, the main advisory panel to the National Institute of Neurological Disorders and Stroke (NINDS).

NINDS, a component of the National Institutes of Health (NIH), is the nation's primary supporter of basic, translational and clinical research on the brain and nervous system. The NINDS Advisory Council is composed of physicians, scientists and representatives of the public, who review applications from scientists seeking support through government grants for biomedical research on disorders of the brain and nervous system. NINDS Advisory Council members also advise the NIH on research program planning and priorities.

"In just a few years, Mr. Gross has done a remarkable job of engaging engineers, scientists and clinicians in plans to develop research that will lead to better treatment for people with hydrocephalus," said Story Landis, Ph.D., Director of the NIH National Institute of Neurological Disorders and Stroke (NINDS). "I am delighted that he will be a member of the NINDS Advisory Council and look forward to his participation."

The HCRN is delighted as well and offer sincere congratulations to Paul on this appointment. Paul brings his entrepreneurial perspective, successful business experience, and a deep, passionate commitment to finding answers for people living with hydrocephalus.

HA Representatives Invited to HCRN Investigator Meetings

Gavin Reed, the research associate at the Hydrocephalus Association attended the semiannual HCRN meeting held in Salt Lake City on November 9 – 10, 2011. This meeting gave Mr. Reed the opportunity to learn about HCRN and its studies, and to represent HA at the meeting as part of the organizations' expanding partnership. The next meeting, to be held in Houston, Texas in May 2012, will be attended by Ms. Dawn Mancuso, the new CEO of HA. The HCRN is pleased to have the opportunity to meet Ms. Mancuso at this upcoming meeting and to continue finding ways in which the combined forces of these two organizations can better serve pediatric hydrocephalus patients and their families.



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Please be sure to see them by visiting our website at:

<http://www.hcrn.org>

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To make a contribution to the HCRN

Please contact Douglas Nielsen at Primary Children's Medical Center Foundation at (801) 662-5970. All contributions are tax deductible as allowed by the IRS.